

University of Groningen

## **Making sense of risk. Donor risk communication in families considering living liverdonation to a child**

Knibbe, Mare; Verkerk, Marian

*Published in:*  
Medicine, Health Care, and Philosophy

*DOI:*  
[10.1007/s11019-009-9226-7](https://doi.org/10.1007/s11019-009-9226-7)

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2010

[Link to publication in University of Groningen/UMCG research database](#)

### *Citation for published version (APA):*

Knibbe, M., & Verkerk, M. (2010). Making sense of risk. Donor risk communication in families considering living liverdonation to a child. *Medicine, Health Care, and Philosophy*, 13(2), 149-156.  
<https://doi.org/10.1007/s11019-009-9226-7>

### **Copyright**

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

### **Take-down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

# Making sense of risk. Donor risk communication in families considering living liverdonation to a child

Mare Knibbe · Marian Verkerk

Published online: 1 November 2009

© The Author(s) 2009. This article is published with open access at Springerlink.com

**Abstract** This paper contributes to the growing line of thought in bioethics that respect for autonomy should not be equated to the facilitation of individualistic self determination through standard requirements of informed consent in all healthcare contexts. The paper describes how in the context of donation for living related liver transplantation (LRLT) meaningful, responsible decision making is often embedded within family processes and its negotiation. We suggest that good donor risk communication in families promote “conscientious autonomy” and “reflective trust”. From this, the paper offers the suggestion that transplant teams and other relevant professionals have to broaden their role and responsibility for risk communication beyond proper disclosure by addressing the impact of varied psychosocial conditions on risk interpretation and assessment for potential donors and family stakeholders. In conclusion, we suggest further research questions on how professional responsibility and role-taking in risk communication should be morally understood.

**Keywords** Living related liver transplantation · Risk communication · Autonomy · Trust · Family decisions · Family processes

**Subsidy** This study is subsidized by the College voor Zorgverzekeringen (CVZ), a government organisation concerned with evaluation and implementation of health insurance legislation.

M. Knibbe (✉) · M. Verkerk  
Department of Health Sciences, University Medical Center  
Groningen, University of Groningen, Expert Center Ethics of  
Care, 9700 RB, Groningen, The Netherlands  
e-mail: m.e.knibbe@med.umcg.nl

## Introduction

When healthy individuals consent to undergo an operation solely to benefit another, the communication of the risks of that operation bears a special weight and significance. Risk communication can change processes of decision making and shape the moral significance of decisions to donate or not to donate, supporting but also disturbing the complex collaborative endeavors of care and decision making within which this communication takes place. This paper offers an analysis of two complex cases of risk communication in the situation of a family member donating a part of his liver to a child. The two examples are exceptions rather than exemplary cases, but they can help us draw attention to aspects of risk communication in families that often go unnoticed when they go well. We will argue in this article that important aspects of risk communication are difficult to grasp in the terms of a dyadic relation of physician and donor; they can only be understood when placed in the broader social context of the changes that a family undergoes in the process of decision making. Starting with these two complex cases, we explore what risk communication entails in this context of a family living through transitions. In the bioethics literature, risk communication has been most discussed as part of informed consent procedures. Without denying the importance of informed consent, we direct attention to other interactions and processes of change in which risk communication gives and gains significance.

Risk communication gains and gives significance in family processes that overlap with decision making. Risk communication, we argue, should be understood in the context of giving significance to transitions in the family, not only as an unhampered exchange of information between potential donor and professionals. This means

that good risk communication does not only depend on professionals who disclose risk information; it also depends on family interactions that are beyond the control of professionals. To understand what good risk communication in this family context may be, we propose a broad notion of autonomy, and we outline the reflective kind of trust in family relations that can support such a form of autonomy.

There are no a priori given roles that professionals can and should play in the transitions that these families go through. The tradition of respect for autonomy and respect for the private sphere of the family of patients and donors holds that the interference of professionals in family matters should be limited. We argue, however, that the offer of living related liver transplantation (LRLT) for a child in itself is not morally neutral: it conveys the message that LRLT is an acceptable option and that parents can be expected to feel responsible to donate a piece of liver to their child. The offer of LRLT already interferes in family life. Professionals should therefore try to interfere in a good way, rather than refrain from interference. Although professionals cannot lay down the terms for risk communication in the family, they can adjust their own 'share' in family processes. We will conclude our article by suggesting further research questions on how the professional responsibility and role-taking should be morally understood.

This discussion of donor risk communication is based on a study that is part of the research project entitled "Living Related Donation: A Qualitative Ethical Study," carried out at the University Medical Center Groningen. For this study, we conducted semi-structured interviews with 22 parents, two uncles, and one aunt of 12 families who had considered living liver donation for an infant transplant patient. A short conversation was held with a second aunt in the course of the interview with her husband. This conversation is also used in this paper. In the case of four families LRLT had been done. In the case of the other eight families, LRLT had been postponed or abandoned for various medical or psychosocial reasons. If LRLT was postponed it was often kept as a safety net. In that case, the family would wait for a post-mortem donor liver, but when the condition of the child deteriorated too much on the waiting list, they would opt for LRLT. In these eight families, the patient had been transplanted with a post-mortem graft. In addition, the weekly meetings of the liver transplant team and the outpatient pediatric clinic were attended.

The views in this paper are developed on the basis of observations and interviews in one liver transplant center with its own ways of handling donor risks. Yet, our proposed ways of framing risk communication can be of broader use to other centers and ethicists as well.

## Complications in family processes

When Baber needed a liver graft from his uncle Jamal, his transplantation became a contentious event. This uncle had a special bond with his nephew, since he had always joined Baber's family, of Asian origin, in the hospital as an interpreter. He was the best Dutch-speaking member in the family. When both parents were deemed medically unsuitable as donors, Jamal volunteered to donate. Jamal's wife reports that she had been very scared: *'I was very scared when he was going to donate; I didn't know what would happen. I tried to stop him, ... but he didn't listen to anybody, he only saw the baby [Baber]. ... He told me there was only a small risk, but even then I was scared'*. In this short account of fear about what could happen, she recalls her husband's disregard of risk: he thought the risks were small and he listened to nobody: *'he only saw the baby'*. Professionals seemed to have a more remote and mediated presence in her account. When her husband told her that there was only a small risk, he summarized the general message he had picked up from professional risk communication. However, she was neither impressed nor reassured by this communication. Jamal indicates that his wife and other family members had heard other, more frightening stories about living donation. Jamal found the risks small and acceptable, but the rest of his family had very different ideas about the magnitude of the donor risks.

Since nobody could stop Jamal, Baber's parents were pressured by other family members to refuse the offer to donate. Baber's mother reported, *'We didn't want him to donate, (me and my husband) because if something would happen to him, we would feel very guilty and ashamed before the family; we were very scared.'* However, they were also pressured by Baber's uncle to accept his offer. He first tried to persuade the whole family by explaining how thorough the screening procedures for donor candidates were. When the parents, fearing the reproach of other family-members, later continued to oppose LRLT, Jamal put them under more pressure. Uncle: *'I told them; you heard what the professor said; he has no more than four weeks to live if we do not operate on him now. What do you want? ... If you give up on your child, please give him to me.'* This way of framing their decision put Baber's parents in an even more difficult position. They kept wavering, agreeing one moment, withdrawing their consent in the next moment. Finally, after the mediation of a generally respected great-uncle, Jamal managed to get their consent to his giving Baber a piece of his liver. After the transplantation, both Baber and Jamal recovered. Jamal was a family hero; however, Baber's parents still had a difficult relationship with the rest of the family.

The donor decision in this case seems to meet the ideal of informed consent; Jamal was well-informed, and there

was little doubt about the voluntariness of his decision: he was clearly very motivated to donate since he resisted the family pressures to withdraw from liver donation. Nevertheless the communication about donor risks in this family seems far from ideal, especially because, as we will argue below, it did not support the maintenance of trust relations in the collaborative decision making process.

In another family, Elske, a mother of a liver transplant patient and one of the potential donors, was overwhelmed by the information about donor risks: she kept fretting about them, unable to make up her mind. Many of her family members were opposed to living liver donation. The aunt of the patient connected doubts about Elske's possible donor status to specific expectations she had of mothers: *'because I thought, being a woman, she is the one who keeps the family rolling, what happens if she is in the hospital?'* In the interview with Elske and her husband, the differences in the way they discuss living donation and its risk is striking. To Elske it was a practical and religious issue, brought home to her by other family members:

I was also more sensitive to comments of others ... like how will things go with the family if you have medical complications, such things ...or are we not going too far? [from a spiritual viewpoint]... I've never faced such difficult things.

To Elske's husband, who was also screened, living donation and its risk had been a more intellectual and religious issue. In the interview he never mentioned practical concerns about family care and positioned himself as a more independent thinker, less sensitive to comments of family members. He had studied Bible fragments that could have a bearing on the question, and he had thoroughly considered all the risk information given by professionals. Moved by the suffering of his son, he became convinced that, if he were a suitable donor, he should pursue living donation. Elske's concerns did not seem to have any salience to her husband; according to him, she was under the influence of the more traditional side of the family, where such things were difficult to discuss. Elske herself, keeping the family rolling, seemed to lack space and peace of mind to determine her position about living donation or to consider its risks. She felt very frightened, but she also felt unable to refuse to donate. *'You don't know what you're at..., what will happen to the family if something happens to me, these things. They were the most difficult things I ever encountered.'* This made it difficult to give the risks and risk-related fears a place in the decision making process. She entered the donor trajectory, although thoughts about worst case scenarios kept haunting her. Risk awareness seemed to be paralyzing to the degree that refusal as well as consent to donation was extremely difficult. Even though she was properly informed, as part of the informed consent

procedure, she felt unable to act. Information thus was not enough to support autonomous decision making.

### Donor risk communication: giving significance to changes

Elske's fretting response to considerations of risk and the familial tensions in Baber's family point to problems with donor risk communication that have rarely been discussed. These problems can only be understood if we pay closer attention to the family setting in which living liver donation is considered. Up till now the communication of donor risks has been discussed mainly as an issue of informed consent. Those discussions of donor informed consent are primarily concerned with donors' frequent disregard of the risk to themselves. Such disregard of risk has been observed in other studies and was also reported by different respondents in our study (Fellner and Marshall 1968; Fellner and Marshall 1970; Crowley-Matoka et al. 2004; Knibbe and Verkerk 2008). Many donors spontaneously decide to donate, without considering the risks of living donation. Several ethicists point out that these donor attitudes call for a rethinking of common models of informed consent and autonomous agency (Sauder and Parker 2001; Spital 2004; Crouch and Elliot 1999). The fretting response to risk communication poses fewer problems in view of informed consent norms as they are commonly understood, because this response seems to testify of awareness of the donor risks involved: the information about the possibility of death or of compromised recovery after donation has clearly been picked up by those fretting about risks. Yet this risk awareness can be disturbing or troublesome in the experience of parents as potential donors.

The complexities we sketched above can be viewed as problems of adjusting and giving significance to the turbulent changes in family life brought about by the infant's life-threatening illness. Therefore, the communication of donor risks should not only support individual decision making, it should also be supportive of these changes a family is going through. Jody Halpern and Margaret Little point out that risk communication should take into account that people can only do something with the information given if they are able to maintain a sense of themselves and a sense of meaningful connections to a world that is relatively safe and familiar (Halpern and Little 2008). In the context of living related liver transplantation this task of maintaining or finding a new sense of self and (life-) world is a collaborative family process. Families undergo changes and are sometimes even disrupted: in the case of Elske, there was a need for reconsidering the habitual practice of family care. In the case of Jamal, established family relationships came to stand under pressure.

In the case of Elske, the changes in the family involved responding to the needs of the sick child while providing continuity in spite of the child's life-threatening disease. The new caring needs of the sick child put extra burdens on parents. In order to cope with these extra burdens, the parents regulated attention, caring activities and emotions in specific ways. Role divisions between parents often helped to distribute burdens of care. Paying attention to risks could also become one of the 'burdens' that were distributed.

If we follow how attention to donor risks is distributed among family members, risk communication can be confronted with the kind of critical perspective on gender or other inequalities with which divisions of labor or distributions of burdens in care are often viewed. Gendered divisions in care for the sick child and family can make things easier. However, as is often the case with role divisions, they are not always well balanced. In some families, it seems that mothers carry the heaviest burdens of care. The donor risks thus gained significance in the context of gendered social schemes. Elske's fretting responses to risk communication can be placed in this context. It is difficult to sketch role divisions on the basis of interviews. The frayed edges of role divisions often become more visible in what people do than in what people say about them. Yet, some differences in the stories of Elske and her husband can help to lay out the precarious position Elske found herself in. In the interviews in Elske's family, it seemed that the continuity of family care was particularly dependent on her. With this lonely and big responsibility, she could not find the peace of mind to give attention to donor risk a place in her decision. Elske did not consider the risks. Instead, she was haunted by worst-case scenarios. Rather than making up her mind, she postponed the decision and hoped that the doctors would decide that she was not a suitable donor.

Although Elske did not become a donor in the end, her reception of donor risk communication seems similar to donor experiences described by Forsberg et al. They write: *'Decisions were arrived at and preparations were made, often with the donor in a state of mental stress and traumatized by the whole situation'* (Forsberg et al. 2004). Instead of enabling potential donors to decide and prepare, risk awareness undermined their capacity to respond to the problems of their situation.

Elske found no space to negotiate her position in family care. In her case we could say that the donor risks *gained* significance in specific family care practices. However, contemplating the donor risks did not lead to *giving* or finding new meaning in the changing family practice. Elske was placed in a social scheme that was difficult to revise. With five children, one of whom had a life-threatening disease, Elske had great difficulties meeting all the demands of care made on her. In this position she could

hardly think about the additional problems posed by living donation and its risks. She found herself alone with concerns that had no salience to her husband and with too heavy a burden of care.

In Baber's family, family relations were challenged by different attitudes toward LRLT and the risks it involved. The measure of readiness to donate or to accept an offer to donate can potentially be seen as an expression of one's commitments to the recipient or to others. Different risk attitudes and reactions to the option of living donation can confirm as well as challenge relations in the family. Contemplating the donor risks can give new and sometimes threatening meanings to family relations. In Baber's family, Jamal saw living liver donation as an affirmation of the special bond he had with his nephew. Many other family members had made it clear that they would blame Baber's parents for any resulting harm to Jamal if they gave their consent to LRLT. Jamal on the other hand tried to convince his family that donation was his own decision and responsibility, and that any harm to him could not be blamed on Baber's parents. He did, however, reproach Baber's parents for withholding their consent to LRLT and thereby endangering the life of their child. Baber's parents had very little room to articulate their own position. They did not manage to position themselves with regard to the donor risks. Instead, the risks and the family's opposing understandings of risks positioned them either as blame-worthy or as careless parents. In that way, considering the donor risks led to new moral meanings in this family.

### Good risk communication

When LRLT is seen as a family matter and risk communication as a collaborative process that gains and gives significance in changing family circumstances, good risk communication must be understood in this context of family transitions. The conditions or barriers for decision making of individual donor candidates are created in family context. Therefore, family relations and practices are important: donor risks gain significance in these family relations and practices. However, the maintenance of good family relations and values in this period of transition can also be seen as a valuable end in itself. The changing significances given to family relations in the light of donor risks should therefore be taken into account in notions of good risk communication. We propose first, that risk communication should be framed by a broad notion of autonomy in which psychosocial conditions for reflection are addressed. Second, we propose that good risk communication should also support the maintenance of trust in family relations. After outlining these notions of autonomy and trust, we indicate how the importance of family

processes puts the encounters between potential donors and their physicians into perspective.

### Reflective endorsement of norms that govern liver donation

As Elske's story illustrates, adequate and relevant information is not by itself sufficient for making a decision. As was shown, Elske was well informed but felt unable to act, she was unable to give either consent or refusal. In order to participate and act out of her own accord in the practice of LRLT, she would have to become more familiar with the norms that govern this medical practice. Before LRLT became an issue she lived according to her views of good motherhood, good church membership, good daughterhood, but in this new and unfamiliar practice of LRLT, the norms that had governed her life did not tell her what to do.

One of the challenges of the transitional period leading up to transplantation, becoming accustomed to an unfamiliar medical practice, also has implications for notions of autonomy. The notion of "conscientious autonomy" put forward by Rebecca Kukla can be useful in this context (Kukla 2005). Kukla describes conscientious action as 'responsible commitment to the norms that govern it' (p 38). In this view, actions are not autonomous because they were self chosen: actions are autonomous when they are in keeping with someone's commitments. Kukla further argues that conscientiousness or responsible commitment to certain norms or practices require that one is capable of stepping backward and questioning commitments. To become autonomous in this sense, after "tumbling" into an unfamiliar medical practice with its own particular norms and habits, parents have to reorient themselves. The report of Elske's husband about his decision to be screened for donation can be seen as a textbook example of reflexive endorsement of norms. He studied and reconsidered both the norms inherited in his religious community, and the norms that governed the medical practice of LRLT. After thorough reflection, he became convinced that living liver donation was a good option. Elske however, in her position in which the family seemed to be dependent on her being able to run it, was unable to take such a distance, to step backward and question her commitments. Professional concerns about the autonomy of potential donors are therefore best addressed by creating conditions for the process of reorienting; interpreting; and responding.

### Reflective trust

To create conditions for such a form of conscientious autonomy, parents or other donor candidates need a

specific kind of trust from their partners or other family members that are involved in decision making. We propose that good trust here is a reflective kind of trust in which family members allow each other to step backwards and question the norms that guide decisions about living donation. Trust can support such conscientious autonomy, but some forms of trust can exercise moral pressure and thus make it difficult to step backward. As Margaret Urban Walker points out, in trusting others, we hold them responsible. 'I propose then that we think of interpersonal trust generically as a kind of reliance on others whom we expect (...) to behave as relied upon (e.g. in specified ways, in ways that fulfill an assumed standard, or in ways so as to achieve relied-on outcomes) and to behave that way in the awareness (...) that they are liable to be held responsible for failing to do so or to make reasonable efforts to do so.' (Walker 2006, p. 60) Trust thus involves normative expectations toward others, which may also take the form of moral pressure.

To identify the kind of trust that supports conscientious autonomy it is useful to distinguish different forms of reliance involved in trust. Trust can be a kind of reliance on others to do something or to be disposed to do something. Some family members may trust a mother to accept the risks of liver donation for the sake of the child. If trust takes that form, they may completely lose trust in that mother if she refuses to become liver donor, independent of her motives to do so. According to some accounts of trust, trust also entails belief in the (favorable) motives of the other (Walker 2006; Hardin 2002). A husband may trust his wife to donate out of love for her child and not because of the status or admiration that she could gain from donating. In long lasting close relationships of extended commitment, one can trust the other to have a certain set of motivations in connection to oneself (Walker 2006). We propose that in reflective trust the reliance on this set of motivations and commitments toward the child and family members can be uncoupled from reliance on the other to do something specific, i.e. to become a liver donor for the child. This form of trust was expressed by the husband of a donor candidate, who, in reaction to his wife's hesitations about donation, said: '*Margaret does everything that is in her power and I do what is in my power.*' This way he indicated that his trust in her commitments to her child and family or in her 'set of motivations' remained undamaged even if she would refuse to donate. He showed that the norm that a mother does everything for her child could be questioned without calling her commitment to her child into question.

In the context of LRLT, we propose that good trust implies a form of "reflective trust," that is, that it should take some distance from inherited normative expectations toward parents or other family members involved. In most

of the families included in our study, challenges to relations were addressed by family members. They actively pushed back against normative expectations. In that way they showed that the continuation of trust relations in the family was not dependent on the fulfillment of specific expectations to donate. By contrast, the families of Elske and Baber failed to reconsider some of the inherited normative expectations that governed decision making.

In sum, good risk communication should create conditions for conscientious autonomy and for the continuation of trust relationships in families. Both, conscientious autonomy and the proposed reflective trust in families, depend on whether family members, facing changes, manage to push back against the inherited normative expectations in order to explore future changes. As the cases of Elske and Baber show such normative expectations are often gendered; class bound; and formed in specific religious or cultural communities. Thus, in the context of family decision making, the capacity to understand information about risks completely, seems less important than forming good interpretations about the significance of the donor risks in the family. In the stories of our respondents, it is difficult to isolate risk communication from other issues; it is strongly interwoven with other family processes.

### Implications for professional risk communication

If family processes and risk communication are so closely connected, questions arise about what professionals can and should do to support good risk communication. Further research is needed to get more clarity about good role-taking of professionals in donor risk communication. Below we first describe the kinds of roles that professionals *can* take, roles that were ascribed to professionals by donor candidates, their partners and other family members. We then formulate the questions that have to be addressed in further research, in order to judge which roles professionals *should* take in this broadly understood process of risk communication.

On the basis of our study we can outline the roles that were ascribed to professionals by parents or other family members. In the stories of parents, two types of roles are ascribed to professionals in the family processes. The team helps families interpret and adapt to changes, but it is also part of the changes: professionals represent the new medical practice in which a family must participate. These roles of guiding changes in family life that result from treating the child's disease and of representing an unfamiliar medical practice can be seen as the two roles in which professional risk communication gains significance for parents or other potential donors in the family. When professionals communicate donor risks, they do not merely

sketch possible outcomes and their probabilities. With their style of talking about risk, they also show something to potential donors and partners about the kind of medical and moral practice they have entered.

Respondents registered the attitudes of professionals toward donor risks in different ways. In interviews, respondents remembered very little about the details of the risks that were communicated—the mortality and morbidity statistics or the specific complications that can occur after liver donation. What they remember is the serious tone and emphasis with which risks were communicated and the concerns in the transplant team about these risks. Respondents had collected a general message from this professional communication. In the interviews, they speak about small; big; considerable; or acceptable risks. As one mother reported: *'They were very clear about the risks, with percentages and so forth, I don't remember exactly, only that there was a big risk.'* Some respondents felt impelled to give the risks a great deal of thought, whereas others entrusted risk considerations to professionals. When recalling encounters with professionals in which risks were communicated, the two aforementioned roles of professionals alternated. Sometimes respondents took the general message about donor risk as guidance in their own orientation on questions about living donation; sometimes they took their observations about professionals and professional thoughts and feelings to represent the character of the medical practice they had entered.

Depending on the roles as guides or representatives that professionals receive or manage to play, they have different entrances for supporting risk communication in the family. In a family like Baber's, where stories from different origins circulated about the dangers of living donation, the role of doctors as representative of this unfamiliar medical practice could be an important one. As matters stood, the family (with the exception of Jamal and Baber's parents) had only second- or third-hand stories about living donation and its risk. If Jamal's wife and other opposing family members were invited for a direct conversation, professionals could try to situate the diverse messages and frightening stories about living donors, to try to come to shared understandings about the donor risks and the ways they are handled in this transplant center. When risk information is explicitly communicated as a kind of knowledge that is embedded in a medical subcommunity with certain values, worries, and interests of its own, family members can relate in their own ways to this new and unfamiliar community.

In Elske's family the guiding role of the transplant team, in helping this family handle the changes in family life, could maybe be enlarged to help her make up her mind. The guiding role of professionals in the transplant team (doctors, psychologists or social workers) could be understood in a way similar to that of the "gift-exchange gatekeeper," as



Fox and Swazey describe the role played by medical teams in family-processes. They write that since the gift of an organ puts strains on family relations, gift-exchange gate keeping implies negotiating, mediating and interpreting what happens between family members (Fox & Swazey 1974). In the cases they describe, the involvement of social workers or psychiatrists sometimes brought about significant changes in family relations, before everyone agreed with the living donor kidney transplantation. It is however the question how far such interference in family dynamics should go. In Elske's case, the usual conversation that the social worker has with donor candidates about donation did not help her to make up her mind. As we suggested above, the problem could be that she lacked space and peace of mind to think about living donation and its risk because the whole family was dependent on her, or at least so it was thought. Perhaps good risk communication in this family would have to be accompanied by an examination and revision of the gendered social schemes. However, the question is whether that is something transplant teams can or should have a role in.

In both families the options that professionals seem to have to support good risk communication would mean interfering not only in medical decisions but also in social, normative, and even existential issues in families. The question thus rises how far professional interference in family issues should go, what kind of professionals should be involved and what limits should be put to their interference. The account of good risk communication we gave up to here ascribed great weight to family processes. Family processes of giving significance to changes had impact on risk communication and vice versa, risk communication had impact on family relations and care practices. The encounters in which professionals communicate about the donor risks with potential donors are often not the most central interactions in which the donor risks gain significance for potential donors. Furthermore, decision making does not take place in a dyadic patient physician relation; it takes place in a complex network of relations involving potential donors; patients; family members; and members of the transplant team. From our account about risk communication, two diverging normative conclusions can be drawn about professional responsibilities.

One could conclude that the responsibility of professionals in ensuring good risk communication should be modest, since views on risk are most effected by family relations and care practices in a family. In this view, professional efforts to improve risk communication should not intrude in this domain of the family. Professional modesty and putting limits to the interference of professionals in family relations and values is a way of enacting the principle of respect for autonomy with an emphasis on negative freedom. Refraining from too much interference is also a

way of dealing with cultural differences. In healthcare relations, there is always a risk that the culturally and institutionally inherited values and norms of professionals come to dominate the values and norms of patients and family members. Professional modesty can be a way of avoiding such domination.

Although we share the concern that interference in family life should not go too far, we also have to take into account that the offer of LRLT in itself already has a big impact on family life. Moreover, the offer of LRLT is not a morally neutral offer: it involves specific ideas about the acceptability of risks and sacrifices and the offer conveys expectations about the responsibilities of parents and family members. Parents and other family members have to think about themselves and each other in new and unfamiliar terms to make up their minds about LRLT.

Taking this inevitable impact of the LRLT offer on family life into account, we think that further research about risk communication should ask how professionals could help to bend the influence that the offer of LRLT inevitably has in the best possible direction. To address this question, descriptive as well as normative work needs to be done. The descriptions we gave of how family members saw professional roles in risk communication need to be complemented by descriptions of the views of professionals on their roles and relations and on the informed consent norms that guide their interactions. Only then can we address the more normative questions about what good professional risk communication is and how the informed consent procedure is best understood in the context of LRLT.

## Concluding remarks

The significance of donating or not donating in a family cannot be defined by the potential donor alone; it is carried by different family-members. Attitudes towards donor risks in the time leading up to transplantation account for a great part of the moral meanings. Family attitudes toward the risks to donors and the negotiations and interpretations of risk attitudes in the decision making process make living donation or refusal to donate morally acceptable or unacceptable to family and professionals. At least as important as individual donor considerations are the connections between considerations of risk of the different participants in this practice.

The different attitudes were connected and adjusted in processes of familial care and redefining of familial relations—processes that also interfered with decision making. Giving attention to risk was often one of the many burdens that were divided in these processes among parents and professionals. With their diverse forms of attention to



donor risk, respondents placed themselves, including their fears and concerns, in different positions in the collaborative endeavor of family care and in relations to the patient, donor, or other family members. When different attitudes toward living donation and its risk seemed to challenge family relations, family members often tried to interpret and accept each other's attitudes in more harmless ways, in order to reduce pressures.

In the two cases we discussed, family members took, or allowed each other, little space to negotiate their position in care or in family relations. Respondents did not place themselves; they were placed in a social scheme that was difficult to revise. Respondents' positions in social schemes of family care and family relations could dispose them to attend to donor risks in certain ways. It seems that a certain fluidity in role divisions is required to give donor risks a place in decision making: in reflective trust, family members allowed each other to step back and question the norms that guided decisions about donation without calling the more general background commitment to the child or to other close family members into question. By contrast, rigidity of roles that were not open to reinterpretation could make it very difficult to place the donor risks in the course of decision making.

Although good risk communication depends largely on family processes and relations that are beyond the control of professionals in the transplant team, it also depends on the relations between family and team and the roles that the team and its professionals played for a family. On the basis of our study we outlined the roles that were ascribed to professionals by donor candidates and their families. Professionals received different roles in the processes of change a family was going through; they could be seen as guides in a turbulent time, or as representatives of an unfamiliar medical practice. In some families, medical professionals—as representatives of an unfamiliar practice—can support risk communication by expressing the team's concerns about the donor risks and the ways they are handled. By making potential donors familiar with the concerns and norms that govern the practice of living liver donation, professionals can create conditions for conscientious autonomy. In other families, members of the transplant team may need to examine how gendered role divisions have a bearing on the significance of living donation and its risk.

To judge how professional roles in processes of risk communication can best be understood, further research is needed in which the understandings of professionals about their roles and relations are mapped and critically compared to the understandings that families have about

professional roles and relations. On the basis of such research, inherited normative understandings about the scope and limits of professional roles in the complex networks of relations between family members and team members can be reconsidered.

**Acknowledgments** We thank the liver transplantation team in Groningen and the parents of transplant patients or other (potential) donors for their openness and cooperation with our study. We thank Hilde Lindemann and two anonymous reviewers for their helpful comments on language and content of an earlier draft of this paper. This study was approved by an accredited Medical Review Ethics Committee (aMREC).

**Open Access** This article is distributed under the terms of the Creative Commons Attribution Noncommercial License which permits any noncommercial use, distribution, and reproduction in any medium, provided the original author(s) and source are credited.

## References

- Crouch, R.A., and C. Elliot. 1999. Moral agency and the family: The case of living related organ transplantation. *Cambridge Quarterly of Healthcare Ethics* 8: 275–287.
- Crowly-Matoka, M., M. Siegler, and D.C. Cronin. 2004. Long-term quality of life issues among adult-to-pediatric living liver donors: A qualitative exploration. *American Journal of Transplantation* 4: 744–750.
- Fellner, C.H., and J.R. Marshall. 1968. Twelve kidney donors. *Jama-Journal of the American Medical Association* 206: 2703–2707.
- Fellner, C.H., and J.R. Marshall. 1970. The myth of informed consent. *American Journal of Psychiatry* 126: 79–85.
- Forsberg, A., M. Nilsson, and M. Olausson. 2004. The essence of living parental liver donation—donors' lived experiences of donation to their children. *Pediatric Transplantation* 8: 372–380.
- Halpern, J., and M.O. Little. 2008. Motivating health: Empathy and the normative activity of coping. In *Naturalized bioethics; toward responsible knowing and practice*, ed. H. Lindemann, M.A. Verkerk, and M.U. Walker, 143–161. Cambridge: Cambridge University Press.
- Hardin, R. 2002. *Trust & trustworthiness*. New York: Russell Sage Foundation.
- Knibbe, M., and M. Verkerk. 2008. Economies of hope in a period of transition; parents in the time leading up to their child's liver transplantation. In *Naturalized bioethics; toward responsible knowing and practice*, ed. H. Lindemann, M. Verkerk, and M. Walker, 162–181. Cambridge: Cambridge University Press.
- Kukla, R. 2005. Conscientious autonomy. Displacing decisions in health care. *Hastings Center Report* 35: 34–44.
- Sauder, R., and L.S. Parker. 2001. Autonomy's limits: Living donation and health-related harm. *Cambridge Quarterly of Healthcare Ethics* 10: 399–407.
- Spital, A. 2004. Ethical issues in living organ donation: Donor autonomy and beyond. *American Journal of Kidney Diseases* 38: 189–195.
- Walker, M.U. 2006. *Moral repair: Reconstructing moral relations after wrongdoing*. Cambridge: Cambridge University Press.